# Urologic Diseases in America

# Interim Compendium









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# UROLOGIC DISEASES IN AMERICA

INTERIM COMPENDIUM

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This book is dedicated to the memory of Dr. Dalia Spektor, 1944–2002.



# UROLOGIC DISEASES IN AMERICA

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# Introduction

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### Introduction

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The burden of urologic diseases on the American public is immense in both human and financial terms and until now has remained largely unquantified. Urologic diseases encompass a wide scope of illnesses of the genitourinary tract, including conditions that are congenital and acquired, malignant and benign, male and female, medical and surgical. They can occur at any point in the course of human development, from hydronephrosis in utero to urinary incontinence in the elderly. They may be acute and self-limited or chronic and debilitating, may primarily affect quality or quantity of life, and may be financially insignificant or catastrophic. Some urologic diseases present with complex signs and symptoms and require extensive evaluation, while others present with classical symptoms and are easily diagnosed. Still others occur without any symptoms at all and are discovered incidentally or during screening. For many urologic diseases the etiology is well understood, and the natural history is fairly predictable. As is the case with many organ systems, physician practice patterns for treating both common and uncommon urologic conditions vary widely and have evolved substantially during recent years.

Accurate information on the epidemiology and impact of urologic diseases is critical to the equitable allocation of scarce resources at the national, state, and local levels. Indeed, as the American population ages, there is a growing need for information about the urologic health problems facing older adults. In conjunction with findings from clinical studies and basic research on biological mechanisms, an epidemiologic approach offers insights on

the prevalence, etiology, and impact of urologic conditions. This information can provide the basis for planning health care services and intervention programs (1).

Despite the need, reliable and valid health services data about urologic diseases have been scattered, inconsistent, and not readily available. The capabilities of the information age highlight this deficiency. There is no national surveillance system describing prevalence and incidence across all urologic diseases. Instead, various government and non-government agencies in the United States maintain a patchwork of population-based studies, observational cohorts, national interview surveys, reviews of physician practice patterns, hospital system databases, regional cancer registries, state health department health information systems, and federal, state, and private insurance claims-based datasets that can provide useful health statistics. These sources contain a wealth of epidemiologic and health services information about health care costs, access, and quality, as well as trends in the diagnosis and management of urologic diseases; however, the information sources remain largely untapped.

The overall objective of this project, *Urologic Diseases in America*, is to quantify the burden of urologic diseases on the American public. We undertook this effort with the aid of sophisticated research methodologies and experienced analytic and administrative staff. Our team included epidemiologists, health economists, statisticians, programmers, and urologists trained in health services research. We searched all potential data sources for

relevant information and health statistics in order to gather current and retrospective data on all aspects of the epidemiology, practice patterns, costs, and impact of urologic diseases in the United States. This volume is intended to convey meaningful information to users at various levels of medical sophistication, including the public, elected leaders, government officials, non-governmental organizations, media outlets, physicians, nurses, allied health care personnel, and academic researchers.

We began our work by conducting an exhaustive nationwide search for all possible sources of health data for urologic diseases in America. This search included data sources such as the large population surveys maintained by the federal government (e.g., National Center for Health Statistics), health care financing agencies (e.g., Centers for Medicare and Medicaid Services), hospital consortia, insurers, physician groups, state and county medical associations, physician specialty societies, private health care foundations, private sources, and the published literature. After defining a universe of potential data sources, we assessed each one on the basis of relevance, reliability, validity, quality assurance mechanisms, accessibility, cost, userfriendliness, and other factors determined to be important to researchers and the public. guidance from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), we selected the datasets most likely to provide useful information (Appendix A). These included datasets from the Centers for Medicare and Medicaid Services, population-based datasets, datasets with information about health care utilization and costs, and those with unique features or populations of interest that added dimension to the project.

We stratified the scope of urologic practice into twelve discrete clinical areas for analysis. Because resources were limited, we were unable to address certain less frequent urologic diagnoses. Table 1 lists the conditions selected for inclusion in the *Urologic Diseases in America* project, the first four of which are covered in this interim compendium.

For each condition, clinical and coding experts developed a set of codes from the National Center for Health Statistics' International Classification of Diseases, 9<sup>th</sup> revision (ICD-9), the American Medical Association's Current Procedural Terminology (CPT),

Table 1. Conditions analyzed in *Urologic Diseases in America* 

Urolithiasis

Benign prostatic hyperplasia and lower urinary tract symptoms

Urinary incontinence

Female

Male

Pediatric

Urinary tract infection

Female

Male

Pediatric

Sexually transmitted diseases

Pre-natal hydronephrosis

Vesicoureteral reflux

Posterior urethral valves

Ureterocele

Ureteropelvic junction obstruction

Male reproductive health

Erectile dysfunction

Peyronie's Disease

Infertility

Undescended testis

Urethral diseases

Hypospadias

Stricture

Interstitial cystitis and chronic prostatitis

Prostate cancer

Bladder cancer

Kidney cancer

Testis cancer

and the Healthcare Common Procedure Coding System (HCPCS) to define relevant diagnoses, diagnostic procedures, and therapeutic interventions. These codes appear in the first table of each chapter. We applied these codes to analytic files from each dataset. Wherever possible, we stratified results into major demographic groups, usually by age group, gender, race/ethnicity, geographic region, and rural/ urban status. We age-adjusted certain tables at the discretion of each chapter author (so indicated in those tables). For certain economic analyses, we constructed multivariate models. Urinary incontinence and urinary tract infection are each divided into three chapters - female, male, and children. The chapters on urinary tract infection are complemented by a special

chapter on sexually transmitted diseases, which was prepared by staff at the Centers for Disease Control. All analytic techniques and further information on the datasets are presented in great detail in the methods chapter.

After completing initial data analyses and constructing draft tables to present information on trends in incidence, prevalence, practice patterns, resource utilization, and costs, we convened a writing committee of academic physicians with experience in health services research and detailed clinical knowledge of our first four conditions. meeting, we also shared with them detailed literature reviews that included all pertinent populationbased epidemiologic and economic studies in the urologic conditions of interest. These individuals provided expert feedback and subsequent input on the execution of additional analyses and refinement of the previous ones. After completing a final set of tables and figures, we asked the writing committee members to provide insight, elaboration, and interpretation - to draw qualitative meaning - on the quantitative findings. The essays they submitted on each clinical topic were subjected to three rounds of formal peer review, which was overseen by an External Consultation and Advisory Committee (ECAC). The ECAC included representation from the fields of academic urology, gynecology, nephrology, internal medicine, as well as experts in claims analysis, Medicare data, epidemiology, and health services research. The ECAC met several times to provide

guidance and feedback on the selection of databases and analyses, generation of data tables, interaction with the chapter authors, and the development of the chapters themselves. After the review process was complete, the ECAC and NIDDK carried out an additional review to ensure accuracy and readability. The resulting chapters on the first four conditions fill this interim compendium. The final compendium, which will be available in 2006, will include all twelve conditions.

Although the chapter authors have worked hard to identify and summarize principal findings for the first four urologic conditions, we encourage both casual and formal readers of the compendium to roll up their sleeves and wander leisurely through the data tables and figures. The chapters are rife with large and small results, some annotated in the text and others waiting to be discovered in the myriad rows and columns. Interested readers could explore any of these findings in more detailed, multivariate analyses. Tables 2 and 3 recapitulate a few of the most salient observations regarding outpatient visits, inpatient hospitalizations, and costs for the most recent years of data analyzed for the interim compendium.

We faced important challenges in our analytic endeavors. Foremost among these was the limited amount of data available for conditions in pediatric urology, particularly the lack of information on the costs of pharmaceutical and medical services. Other methodological limitations are listed in the methods chapter. Furthermore, each chapter concludes with

Table 2. The burden of	urologic diseases i	in America in 2000.
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	Visits to Office-Based Physicians <sup>1</sup> and Hospital Outpatient Clinics <sup>2</sup>		Visits to Emergency	Hospital	Total Expenditures
	Primary Diagnosis	Any Diagnosis	Rooms <sup>2</sup>	Stays	(in millions of \$)1-4
Urolithiasis	1,996,907	2,682,290	614,647	177,496	\$2,067.4
Benign prostatic hyperplasia	4,418,425	7,797,781	117,413	105,185	\$1,099.5
Urinary incontinence					
Female adult	1,159,877ª	2,130,929	*	46,470	\$452.8
Male adult	*	*	*	1,332	\$10.3
Urinary tract infection					
Female adult	6,860,160	8,966,738	1,311,359	245,879	\$2,474.0
Male adult	1,409,963	2,049,232	424,705	121,367	\$1,027.9

<sup>\*</sup>Counts too low to produce reliable estimate.

<sup>&</sup>lt;sup>a</sup>Physician office visits only; counts not available for hospital outpatient clinics.

SOURCES: National Ambulatory Medical Care Survey; National Hospital Ambulatory Medical Care Survey; Healthcare Cost and Utilization Project; Medical Expenditure Panel Survey.

Table 3. Expenditures for Medicare beneficiaries with urologic diseases in 1998.

	Medical Expenditures (in millions of \$)			
	Inpatient	Outpatient	ER	Total
Urolithiasis	\$518.9	\$296.1	\$19.4	\$834.4
Benign prostatic hyperplasia	\$315.0	\$441.2	\$19.8	\$776.0
Urinary incontinence				
Female adult	\$110.1	\$123.7	\$0.6	\$234.4
Male adult	\$11.3	\$27.1	\$0.6	\$39.0
Urinary tract infection				
Female adult	\$687.6	\$210.5	\$58.4	\$956.5
Male adult	\$376.4	\$81.4	\$22.4	\$480.2

SOURCE: Centers for Medicare and Medicaid Services.

specific recommendations for improving the available datasets to support more thorough descriptions of the impact of each condition.

By any measure, the burden of urologic disease on the American public is immense and deserves further attention, in terms of clinical investigation, epidemiologic analysis, and health services research.

Accurately describing the burden of urologic disease on the American public is one of the most important efforts that the NIDDK will undertake at the dawn of the new millennium. Documenting trends in epidemiology, practice patterns, resource utilization, and costs for urologic disease has broad implications for quality of health care, access to care, and the equitable allocation of scarce resources, both in terms of medical services and research budgets. The *Urologic Diseases in America* project represents a major step toward accomplishing those goals.

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1. Fultz NH, Herzog AR. Epidemiology of urinary symptoms in the geriatric population. Urol Clin North Am 1996;23:1-10.